This presentation is a resource developed as part of a face to face education event or workshop.

The target audience is health and social care professionals in roles providing palliative and end of life care

The author has agreed to share the work to enable best practice in the provision of end of life care
Contemporary Challenges in Palliative and End of Life Care

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Content

• Ethical, legal, policy and sociological issues relating to end of life
• 4 Contemporary case studies
• Group work
• Group Presentations and group discussion
• Summary
• References
Why ethics?

• “The question why so many had moral blindness, lacking critical reflection and not thinking it appropriate to raise concerns, remains difficult to understand”
Medical/clinical ethical principles

- What are they?
  - Ethics - principles people use to distinguish right from wrong in the way they interact with the world
  - Moral values and obligations governing clinical practice and enshrined in professionals codes/standards of practice
Ethical reasoning and ethical frameworks

- Ethical reasoning is a term for a philosophical approach to work through the right/wrong, and seeks to understand moral actions and human conduct.

- Ethical frameworks - assist in identifying and seeking to resolve potential competing factors, which have led to ethical dilemmas in real life scenarios.
Ethical theories

• Consequentialism - focuses on consequences of action
• Deontology - focuses on duties
• Virtue ethics - focus on character
Ethical theories 2

- Deontology - the end does not justify the means
- Utilitarianism - the end justifies the means
Bio-medical ethical principles

- 4 bio-medical ethical principles:
  - Beneficence - to do good/benefits must outweigh risks/duty to act in best interests
  - Autonomy - right to decide/the right to be me
  - Non-maleficence - duty to do no harm
  - Justice - fairness (e.g. in process, distribution, relational)

  - Beauchamp and Childress; Principles Biomedical Ethics, OUP, 5th edition 2001
Ethical theories & principles

Sanctity of life

• “all human life has worth and therefore it is wrong to take steps to end a person's life, directly or indirectly, no matter what the quality of that life”.

• Premise is to preserve life
• What about quality of life?
• At what cost?
• Whose judgement?
Acts and Omissions

• there is a difference between actively killing someone and refraining from an action that may save or preserve that person's life.
• A doctor could not give a patient a lethal injection to end his/her life, whatever the circumstances, but could withhold treatment that may sustain it.
Principle of double effect

• argues that there is a moral distinction between acting with the intention to bring about a person's death and performing an act where death is a foreseen but unintended consequence.

• doctrine of double effect allows that performing an act that brings about a good consequence may be morally right even though the good consequence can only be achieved at the risk of a harmful side effect.
Some of the Legal context for end of life challenges

Statutory Law
- Mental Capacity Act 2005 - presumed capacity, protects those who lack capacity, consent, best interests decisions, right to make advance decisions to refuse treatment and to make unwise decisions.
- The Human Rights Act 1998 (ECHR)
- Suicide Act 1961
- Deprivation of Liberty Safeguards (DoLS) 2007
- Proposed new Liberty Protection Safeguards - new legislation to replace DoLS (2nd reading House of Lords July 18)
  - Best interests decisions - ‘necessary and proportionate’ (AMCP for those objecting)
  - HospiceUk involved in shaping new guidance

Case Law:
- Airedale NHS Trust v Bland (1993) - withdrawal of treatment in permanent vegetative state
- Pretty v UK - requesting assisted suicide/right to die
- R (David Tracey) v (1) Cambridge University Hospitals NHS Foundation Trust (2) Secretary of State for Health (2014) -DNACPR
Case law
Withdrawal or withholding of life prolonging treatment

- Life prolonging treatment aims to postpone death e.g. CPR, ventilation, renal dialysis, chemo, antibiotics in some situations, artificial nutrition/hydration

- Withdrawal/withholding life prolonging treatment is legal and moral because it aims to allow a natural death (but may hasten it) if its in overall best interests of person - principle of double effect.
  - the courts do not consider that protecting life always takes precedence over other considerations.
Euthanasia and Assisted Suicide

• Whereas:
  o Euthanasia - is killing on request and defined as a doctor intentionally killing a person by the administration of drugs at that person's voluntary and competent request’

  o Physician Assisted Suicide - is a doctor intentionally helping a person commit suicide by providing drugs for self-administration, at person's voluntary and competent request
Patient refusal of treatment

- Under MCA have right to refuse treatment except basic care.
- ACP - planning ahead
  - appoint LPA to make decisions, as if them, in the event they lack capacity
- ADRT - right to plan in advance to refuse treatment, even life prolonging, providing criteria met
  - Valid and applicable rule
- Right to ask for treatment to be withdrawn but no right to insist on treatment.
‘Basic care’

• Procedures essential to keep a person comfortable
  o Includes warmth, shelter, meeting hygiene needs and offer of oral nutrition/hydration
  o pain relief and other medications to relieve symptoms of distress

• Basic care must be provided except where patients resist actively.
Policies/guidance relating to palliative and end of life care

• Treatment and care towards the end of life (GMC)
• RCN (2016) When someone asks your assistance to die.
• Resuscitation Council (2015) Resuscitation guidelines
• EAPC framework for the use of sedation in palliative care
• Ambitions for palliative and end of life care (2015-2020)
Sociological and political issues

- Aging society
- Scarcity of resources and cost of care - e.g. social care
- Delaying death - use of technology, versus right to die
- Non-communicable diseases rising
- Public pressure e.g. reclassification of substances
- Autonomy versus relational autonomy
- Public perception re choice - CPR
- ‘best bed is your own bed’, but is it?
Cannabis

• Cannabis has now been reclassified under the Misuse of Drugs Regulations to schedule 2.

• There will be no change to its status as a class B drug under the Misuse of Drugs Act so punishments for illicit use are unchanged.

• ‘Cannabis-based products for medicinal use’ is permissive - specialists may consider these products as it will be legal for them to do so

• The products cannot be prescribed [at present] by GPs.
Suicide pacts

• The Daily Telegraph reports the case of a Devon couple in their ’80s who successfully carried out a joint suicide. From the article it appears that this was a rational, well thought out, end of life choice. However, it is unfortunate that this couple needed to end their lives in this way. Perhaps, with more compassionate and flexible legislation they might have been able to have a better death.

• In particular:
  
  o Saying goodbye to their relatives and friends.
  o Avoiding the secrecy and risk of failure of their plans.
  o Delaying their death in the knowledge that there would be medical help to assist in safely and painlessly ending their lives when they felt their quality of life was permanently below the level they wished to accept.
  o Avoiding the shock and distress they undoubtedly caused to their cleaner who discovered their dead bodies, and their family who were unprepared for their action.

A reasoned choice

JULIETTE Hughes asserts that “people only opt for death when they are desperate, lonely, depressed and in pain”. She is mistaken. There are thousands of us that plan to enter the Big Sleep at a time of our own choice. We are mostly not religious, but we are sensible, mature, perfectly in control, good and responsible citizens. Our reason for suicide may be anticipation of pain and incompetence, but quite likely just a sense of a life accomplished and coming to a conclusion.

We are not interested in palliative care, and strongly resent do-gooders placing obstacles in our way. Their activities are illegitimate interference with our liberty and autonomy in a matter most central to our life.

Peter Shaw, Brighton

Ethical framework example:

- This process is captured in the acronym ISSUES:
  - Identify issue/s and decision-making process
  - Study the facts
  - Select reasonable options
  - Understand values & duties
  - Evaluate & justify options
  - Sustain and review the plan
The following questions should be worked through in order.

- **Indications for medical intervention** - establish a diagnosis, what are the options for treatment, what are the prognoses for each of the options.

- **Preferences of patient** - is the patient competent- if so what does he / she want? If not competent then what is in the patient’s best interest?

- **Quality of life** - will the proposed treatment improve the patient’s quality of life?

- **Contextual features** - do religious, cultural, legal factors have an impact on the decision?

Case studies - group work
Summary

- In end of life care, the landscape is constantly changing as we live longer, new technologies/treatments, reduced resources, & the law is tested.
- Contemporary challenges require us to use ethical reasoning - use our moral compass, values and critical reflection to support the best possible care for patients.
Legal references:


• Airedale NHS Trust v Bland: 

• R (David Tracey) v (1) Cambridge University Hospitals NHS Foundation Trust (2) Secretary of State : 
  http://www.bailii.org/ew/cases/EWCA/Civ/2014/33.html


• HSCIC (2014) Information and guidance for the deprivation of liberty safeguards (DoLS) under the Mental Capacity Act 2005 Return. V2.1

• CPS (2014) Suicide: Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide. Crown Prosecution Service 
  https://www.cps.gov.uk/legal-guidance/suicide-policy-prosecutors-respect-cases-encouraging-or-assisting-suicide
Policy and guidelines

- Association of Palliative Medicine (2015) APM Position Statement: Withdrawal of ventilatory support at the request of an adult patients with neurological or neuro-muscular disease
- GMC (2010) Treatment and care towards the end of life: Good practice in decision making. GMC
References 3


• RCN (2016) When someone asks for your assistance to die. RCN

• UKCEN: Ethics - [http://www.ukcen.net/ethical_issues/end_life](http://www.ukcen.net/ethical_issues/end_life)